

Danish cancer patients' perspectives on quality of care from first symptom to end of primary care

L Vindslev Nielsen, G Stentebjerg Petersen and L Aagaard Thomsen

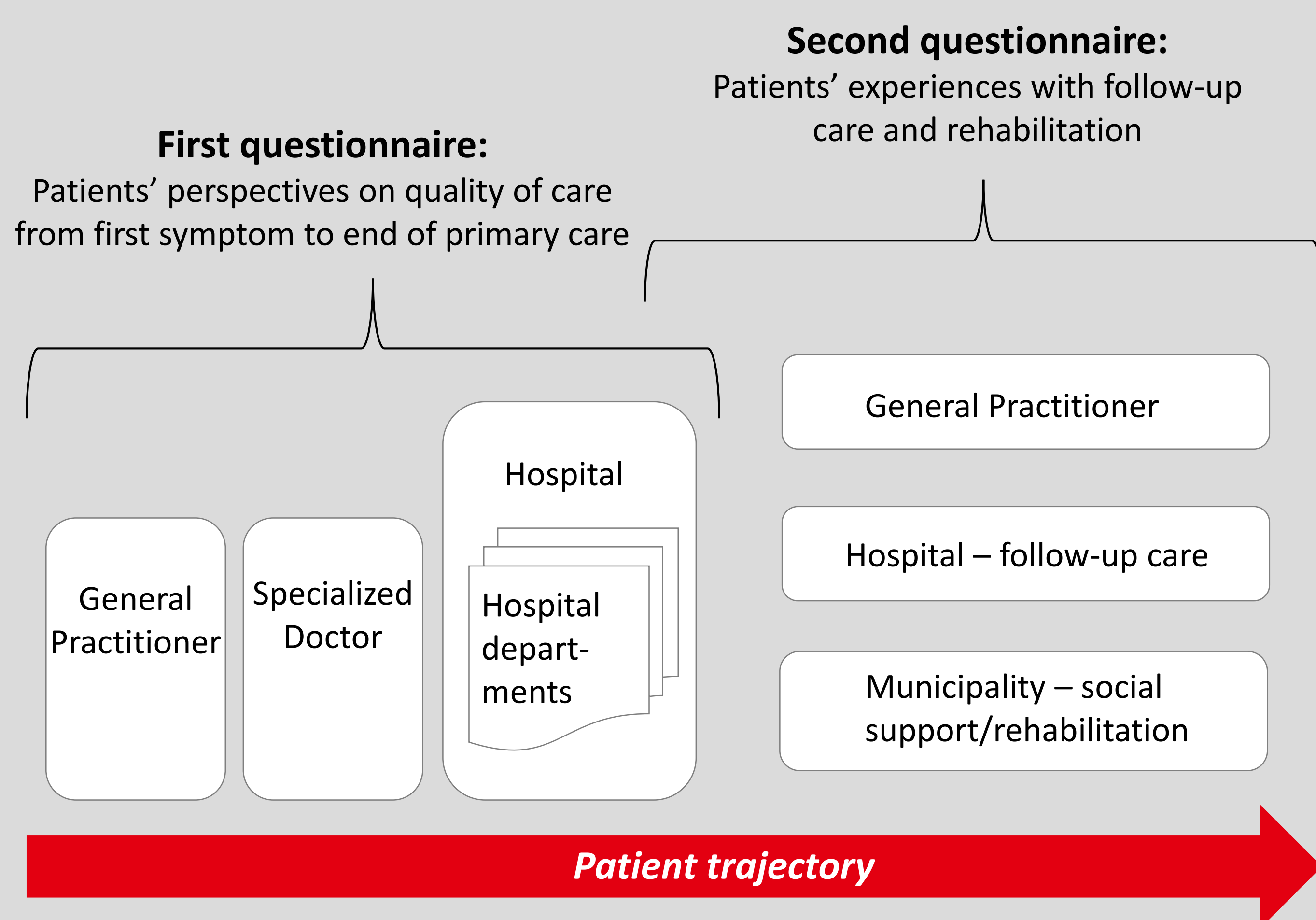
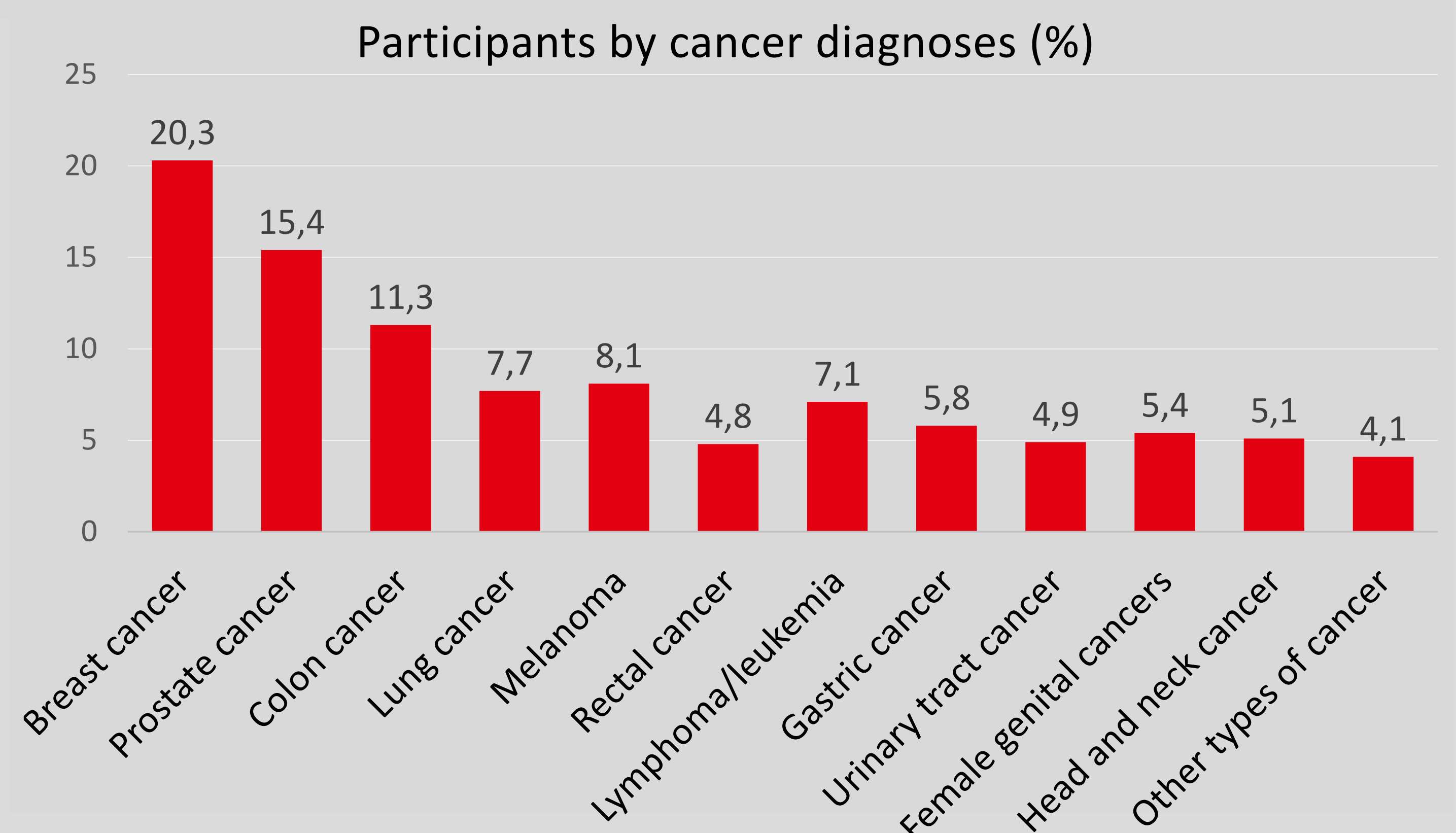
Danish Cancer Society, Documentation & Quality, Strandboulevarden 49, DK 2100 Copenhagen, Denmark

Introduction

The Danish healthcare system is undergoing a shift from a one-sided focus on the patient's disease and its pathology to a more patient-centered approach to quality improvement. Knowledge about the patient's life situation and experiences are now being integrated as important elements in efforts to secure the highest quality standard in treatment and care.

Objectives

To examine Danish cancer patients' experiences with cancer care and treatment and to identify their needs and preferences from first symptom to end of primary care.



Methods

A total of 10.445 Danish citizens between the ages of 30 and 99 registered with a first time cancer diagnosis in the National Patient Registry between July and December 2016 received a questionnaire 4-7 months after they received their diagnosis. Of these 5.389 (52%) responded.

The questionnaire included a total of 182 items (64 from international standardized questionnaires) and addressed themes such as diagnostics, involvement, continuity of care, information and help and support.

Patients included in the survey will receive a follow-up questionnaire in 2019 focusing on their experiences regarding follow-up care and rehabilitation.

Results

The majority of patients are satisfied with the quality of healthcare and experience fast and well-planned patient trajectories. However, there are major challenges when it comes to patient information, continuity and responsibility, different aspects of end of primary treatment and help and support. The study also reveals large variations in patient experiences and needs depending on geography and cancer diagnosis.

Information: Up to 34% of patients report receiving insufficient information prior to undergoing cancer treatment about possible side effects, late effects and complications of the disease and treatment. Moreover, 60 % have not talked to a health professional about how the GP can help them during treatment and 1/3 patients need help avoiding weight change or malnutrition – 59% of these don't get the help they need.

Continuity and responsibility: A number of questions show a lack of doctor responsibility regarding patient trajectory. For example, 30% of patients consider the number of doctors they see during treatment to be too many and 41% have at some point been in doubt about which doctor was responsible for their treatment.

End of primary treatment: 35% of patients do not feel safe being discharged from hospital and a significant proportion are unsure of what symptoms they should be aware of after discharge (41%) and whom to contact in case they need help (22%).

Help and support (rehabilitation): 61% report the need for various types of help and support during their trajectory. Up to 79% of these patients report having unmet needs with regard to physical and psychosocial support, assistance in the home and advice on work or economic issues.

Study population

n=5.389
(52%)



Conclusion

The results show potential for improvement in relation to different aspects of patient-centered care. Our findings indicate a need to focus on the individual needs, wishes, preferences and resources of the patient in order to obtain uniform high quality for all regardless of diagnosis and geography, which calls for a continued and sharpened focus on patient-centered care.

The study is funded by Knæk Cancer.

Corresponding author: Louise Vindslev Nielsen, e-mail: lvn@cancer.dk

